



301 DVD on File FOCUS Alternative Learning Center, Inc.

Specializing in the treatment of children and adolescents who are on the Autism Spectrum, have anxiety disorders, experience processing and social learning difficulties; and who are otherwise, as we like to say, "creatively wired and socially challenged."

Good Afternoon. Thank you for the opportunity to testify today. I am here to support Senate Bill #301: AN ACT CONCERNING HEALTH INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS. My name is Jessica Rhodes. I am here as a School Counselor for FOCUS Alternative Learning Center in Canton. FOCUS provides an excellent therapeutic extended day treatment program for school aged children diagnosed with an Autism Spectrum Disorder (ASD). Just as important, I am here as a mother to wonderful 7-year-old twins, one with Autism and the other with a Learning Disability that exhibits symptoms similar to Autism. We reside in Simsbury.

I am here to advocate for the families I serve and I am here to ask for what my children deserve. Not one child with ASD is alike. However, after much experience in the field, I can say with some authority that mothers of children with ASD are extremely alike. We never get used to our children not getting playdates or birthday invitations. We cry when our children are bullied on the playgrounds and sob because we know bullies will continue to mercilessly target them. We get embarrassed when our "normal looking" children throw a tantrum in the grocery store and people stare, questioning our parenting abilities. Because of this, we avoid going out in public with our children, and if we do, we never do more than one errand at a time. We do not sleep because our children do not sleep. We educate the school systems who misunderstand our child's inappropriate behaviors. We hate the Autism, but LOVE our children fiercely. We face the dilemma of choosing an expensive intervention for one child knowing that other typical children will lose funding for extra-curricular activities. We fear that our "typical" children will have to carry the future burdens of their siblings. We fear our death only because we do not want to leave our Autistic children to be cared for by a system that has already failed them. We neglect our marriages because our children need us more. We do not stop fighting for our children because no one else will. We rarely have full time jobs because no day care can handle our kids. Because of this, we do not have income to pay for services. If we have the good fortune of working, we have the good fortune of getting insurance. We know that insurance is good for the rest of our family, but will deny claims for our child with Autism. So we go into debt to cover the costs of treatment or worse, we don't get the treatment because we already have too much debt. We know that what works for one ASD child may not work for ours, but we are willing to try it anyway. While we waste too much of our limited precious time fighting for services our children are entitled to receive, we will not waste time on a treatment that isn't working. We know

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that Autism is a thief that steals our child's potential, and we know that the right interventions can replace that potential.

And any one of us mothers can tell you that while Autism stinks, we are able to see the blessings it has brought to our lives. We learned to celebrate every milestone as they are few and far between. Our ears NEVER tire of hearing "I love you mommy" as we know we are among the lucky if we are able to hear it. We have become experts at hoop-jumping, in the hopes that it will someday become an Olympic sport. We learned how to become advocates for our children even if we feel uncomfortable doing it. We celebrate the few service providers who do accept our insurance and lovingly work with our children. We do not stop believing that someone out there holds the key that unlocks our child's potential. We never stop advocating because we continue to HOPE that agencies, corporations, federal and state government will stand up and do the right thing for our children. And because we mothers are all member of the Autism club, we welcome all new incoming members with open arms, shoulders to cry on, earfuls of advice, and strategies to beat the system. And we share hopeful thoughts that with mounting numbers like ours, people will no longer be able to ignore our plight.

I know some people are afraid that if this bill passes, schools will feel as if they can get away with doing less. I ask, less than what? No one—no agency, no school system, no government program, and no insurance company has yet committed financial resources to consistently support this population. Schools already do less than they should—they are only equipped to deal with the academic success of our children for 180 days a year for 7 hours a day. Lucky kids will get extended year services for no more than 6 weeks of half-days during an 11 week summer. Some school systems are better than others, but NONE of them are catering to adaptive life skills or social skills as is recommended by Autism experts.

This bill is about getting insurance companies to stop denying our claims because the word "Autism" is attached to our child's name. Much to our distress, no one does enough to help our children. This bill, SB#301, is the place we need to start.

Thank you for your time!

Regards,


Jessica Rhodes, B.S., M.A.

School Counselor/Clinician

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